



**You have downloaded a document from
RE-BUS
repository of the University of Silesia in Katowice**

Title: Moral issues of advance directives

Author: Witold Kania

Citation style: Kania Witold. (2015). Moral issues of advance directives.
"Philosophy and Canon Law" vol. 1 (2015), s. 103-120



Uznanie autorstwa - Użycie niekomercyjne - Bez utworów zależnych Polska - Licencja
ta zezwala na rozpowszechnianie, przedstawianie i wykonywanie utworu jedynie w celach
niekomercyjnych oraz pod warunkiem zachowania go w oryginalnej postaci
(nie tworzenia utworów zależnych).



UNIwersYTET ŚLĄSKI
W KATOWICACH



Biblioteka
Uniwersytetu Śląskiego



Ministerstwo Nauki
i Szkolnictwa Wyższego

Witold Kania

University of Silesia in Katowice, Poland

Moral Issues of Advance Directives

Abstract: The letter *Gratissimam Sane* stresses that contemporary civilization based on utilitarianism treats people like “objects” and not like “persons.” The civilization of use potentially can affect family life. In this context, the paper considers the problem of advance directives. The first part the article offers a historical outline of advance directives which are related to the euthanasia movement and controversial legal battles over patients who lost their capacity to decide. The main reasons for having a living will or health care proxy follow. The second part of the article describes the clinical case of Mr. A., which illustrates the problems regarding the application and interpretation of advance directives. The last part presents a discussion of the case. It focuses on the dignity and autonomy of patient and physician and limits of the proxy decisions.

Keywords: advance directives, euthanasia, health care proxy, autonomy, human dignity

The history of the 20th and 21st centuries is in a major part a great history of human progress. This phenomenon can be observed in the growing capacities of humanity in the area of health care. New drugs and medical procedures allow extending the span of human life. Respirator, artificial hydration, and nutrition, as well as transplant procedures can help in saving life in situations hitherto considered as hopeless. At the same time, all these technical signs of progress can be used in unethical way, subjecting a person to unnecessary suffering. Another dimension of progress is related to the human rights movement and the sense of personal autonomy, which began with the promulgation and adoption of the Universal Declaration of Human Rights in 1948 by the United Nations. In this way, people have become more aware of their rights, and thus they demand respect for their autonomous decisions.

The questions of medical and human rights progress and its ethical consequences can be observed in family life. Every family is the first and the most

important area of crucial decisions regarding life and health issues. This is the first place of mutual respect and love but also of facing difficulties related to ambiguities of human progress.

The Letter to Families *Gratissimam Sane* states that contemporary civilization is linked to the scientific and technological progress which is often understood in a purely positivistic way. This narrow vision of progress leads to utilitarianism in ethics, whose final point is a civilization of production and use. Thus, persons can be treated as objects: “woman can become an object for man, children a hindrance to parents, the family an institution obstructing the freedom of its members.”¹ We can enumerate even more fruits of the civilization of use. Undoubtedly, not only children can become a hindrance to parents, but also parents can be considered a burden to the children. In the midst of a family the issues of ageing and disability and dependency create not only an occasion for service but also the possibility of abuse. The civilization of use is moving people to violate even the most basic human right, that is, the right to life.

The civilization of production and use is diminishing human dignity. If the essence of a human being is understood only in materialistic terms, putting aside all transcendental dimensions, it is difficult to discover the sense of illness, incapacity, and suffering.

The need to preserve personal autonomy in situations of the loss or diminishing of decision-making capacity is one of the reasons for the legal instrument called advance directives.

What Are Advance Directives?

According to the Encyclopedia of Bioethics, “Advance directives are oral or written statements in which people declare their treatment preferences in the event that they lose decision-making capacity. Advance directives may allow patients to prevent unwanted and burdensome treatments when struck by terminal illness, permanent unconsciousness, or profound mental disability.”²

There are two forms of advance directives. One is the *living will* and the other the *health care proxy* or *durable or lasting powers of attorney for health care*. The living will is a type of instructive directives. It is a written statement

¹ John Paul II, Letter to Families *Gratissimam Sane*, 13, February 2, 1994, accessed April 4, 2015, http://w2.vatican.va/content/john-paul-ii/en/letters/1994/documents/hf_jp-ii_let_02021994_families.html.

² G. S. Fisher, J. Tulskey, R. M. Arnold, *Advance Directives and Advance Care Planning*, in Encyclopedia of Bioethics, vol. I, ed. Stephen Garrard Post (New York: Macmillan 2004), 74.

specifying treatment and medical preferences in the case of losing decision-making capacity. The *health care proxy* is a person or persons who are appointed to make or execute care-giving decisions. Many times both forms are placed together in one document.

In other words, advance directives (written living will and appointed health care proxy) are legal instruments which allow people the opportunity to make decisions regarding future life-death and health issues. In the USA and Western Europe, advance directives are known and used by people.³ There are attempts to extend this kind of legal possibility in other parts of Europe.⁴ However, there are certain ethical controversies over this issue.

The History of Advance Directives

The best way to see these controversies is to study the origin and actual practice of advance directives. The history of advance directives begins in the USA. It is related to the new technical possibilities to sustain human life like the respirator, tube feeding or transplants and to the legal mentality of American society which emphasizes freedom, personal autonomy, and self-determination.

The best known promoter of the living will is Luis Kutner, who in 1969 published the famous article *Due Process of Euthanasia: The Living Will, a Proposal*.⁵ Kutner is aware that the act of taking the life of another person is prohibited by law. However, when this action is motivated by human desire to end suffering, it is not always considered as a wrongful act. Mercy killing raises many different philosophical and theological questions. The approach of the article is legal, and therefore it focuses on the review of the current state of the law and presents Kutner's solution of the problem.

Kutner argues that, although in theory of law, mercy killing is not treated differently from other acts of taking human life, in practice its position is different. Public opinion accepts mercy killing more than other instances of murder.

³ Cf. Susane Brauer, Nikola Biler-Adorno, Roberto Adorno, *Country Reports on Advance Directives*, accessed May 3, 2015, http://www.ethik.uzh.ch/ibme/newsarchiv/advance-directives/Country_Reports_AD.pdf.

⁴ About Polish discussion on advance directives, cf. Małgorzata Jantos, "Czy decydujemy o swojej śmierci?," *Kwartalnik filozoficzny* 42, no. 3 (2014): 171–85; Maciej Syska, *Medyczne oświadczenia pro futuro na tle prawnoporównawczym* (Warszawa: Wolters Kluwer, 2013); Marcin Śliwka, Anita Gałęska-Śliwka, "Regulating End of Life Decisions in Poland. Legal Dilemmas," *Advances in Palliative Medicine* 10, no. 2 (2011): 49–56.

⁵ Luis Kutner, "Due Process of Euthanasia: The Living Will, a Proposal," *Indiana Law Journal* 44, no. 4 (1969): 539–54.

It is possible to observe sympathy for the mercy killer and therefore the court or jury have less desire to inflict the same punishment as for other types of taking human life.⁶

In Kutner's opinion, the British and American legal system is not coherent on the issue of euthanasia. On the one hand, it is difficult to defend the victim of someone who is posing as a mercy killer, whereas on the other hand, "the law does not recognize the right of the victim to die if he so desires. He may be in a terminal state suffering from an incurable illness and literally forced to continue a life of pain and despair. Such a denial may well infringe upon an individual's right of privacy."⁷ A legal regulation is needed also regarding the issue of aiding and abetting suicide voluntarily requested by a competent person.

The argumentative strategy of Kutner supporting euthanasia is developed on the basis of the free consent of a patient. The law prohibits mercy killing or aiding in this action. However, an individual has a right to refuse treatment even if its goal is to prolong his or her life. The physician is legally bound by the consent of a patient who can request termination of treatment if his or her condition becomes incurable.

The free consent can be formulated by a competent patient even before the eventual possibility of losing the decision-making capacity. Kutner states: "The patient may not have had, however, the opportunity to give his consent at any point before treatment. He may have become the victim of a sudden accident or a stroke or coronary. Therefore, the suggested solution is that the individual, while fully in control of his faculties and his ability to express himself, indicate to what extent he would consent to treatment. The document indicating such consent may be referred to as 'a *living will*,' 'a declaration determining the termination of life,' 'testament permitting death' [...] or other similar reference. The document would provide that if the individual's bodily state becomes completely vegetative and it is certain that he cannot regain his mental and physical capacities, medical treatment shall cease."⁸

The living will should be confirmed by witnesses. Kutner underlines that the patient is free to change his or her will any time. By this written statement the patient is limiting the authority of the doctor and another medical person on his or her body. The patient can deny treatment and even change the physician.

There are no doubts that Kutner's proposal is controversial. On the one hand, it can be treated as the promotion of euthanasia. On the other, it safeguards the autonomy of the patient in the context of the tyranny of technical possibilities of medicine and a paternalistic approach of medical services.

⁶ Cf. *ibid.*, 542.

⁷ *Ibid.*, 543.

⁸ *Ibid.*, 551.

Kutner's contribution was important in establishing a legal standard in solving healthcare preferences for incompetent patients. But the history regarding advance directives is related also to famous court battles in the USA. There are two well-known cases which are classical in the legal and bioethical literature.

One is the case of Karen Ann Quinlan who, after having taken alcohol combined with drugs, had suffered severe brain damage and was diagnosed in a persistent vegetative state. Her Catholic parents, after long consideration, requested the removal of the respirator that was considered an extraordinary means to sustain her life. The request was brought by the hospital officials to court whose decision became a point of reference in later legislation. According to the verdict of the court, although Karen Quinlan failed to arrange any decision regarding refusal of treatment, her father—guardian could make it on her behalf. The court allowed to forgo treatment if the family would request it. In this way, the ventilator was disconnected, as the family requested. However, Karen did not die immediately. Ten years later she passed due to pneumonia complications.⁹

The second case is related to Nancy Cruzan. In 1983 Nancy had a car accident which resulted in severe brain damage. After recovery from coma she was able to ingest orally some nutrition. To ease the feeding process and rehabilitation surgeons implanted a feeding tube. Unfortunately, Nancy was unable to regain her mental faculties and remained in a persistent vegetative state. Her parents requested termination of artificial hydration and nutrition from the hospital. The hospital refused and the court had to decide. After a long trial in 1990, the court, based on the testimony of witnesses who claimed that in conversations Nancy suggested that being in persistent vegetative state she would not wish to continue on with artificial hydration and nutrition, allowed the termination of this procedure. The life of Nancy Cruzan came to an end. Her case established a constitutional right to end life sustaining treatment when the patient would have wanted such an action.¹⁰

The legal instrument of advance directives was supported by the Congress of the US in 1990. Congress proclaimed the Patient Self-Determination Act (PSDA).¹¹ For institutions like hospitals and nursing homes which receive federal funds (Medicare, Medicaid) the law requires that adults under their care be

⁹ Cf. The President's Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society* 9. (Washington D.C. 2005), 60. Hereafter as *Taking Care*; Robert D. McFadden, *Karen Ann Quinlan, 31, Dies; Focus of '76 Right to Die Case*, accessed May 3, 2015, <http://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html>.

¹⁰ Cf. William H. Colby, *Long Goodbye: The Deaths of Nancy Cruzan* (Carlsbad, CA: Hay House, 2002).

¹¹ 42 U.S. Code Service sections 1395i–3, 1395l, 1395cc, 1395bbb, accessed June 1, 2015, <http://uscode.house.gov/>.

given information about the right to make advance directives. The act of making advance directives should be recorded in medical documentation.

Why Write a Living Will? Reasons to Possess Advance Directives

In recent years, the need of having advance directives was exemplified in the context of a tragic and controversial case of Terri Schiavo.¹² In 2005, Terri Schiavo, a 41-year-old woman from Florida, died after 15 years of being in a persistent vegetative state. Her husband claiming she would not want to be kept alive through artificial means wanted to take her off life support. After seven years of fighting Schiavo's parents, he succeeded in the court and it was ordered to stop her feeding tube. The case was even debated by the Florida legislature and U.S. Congress.¹³ Proponents of the living will say that the bitter family battles over the rights of Terri Schiavo could have been avoided if only she had established her treatment preferences.

The Schiavo case, in which a young person enters a persistent vegetative state after an accident, is not representative of the reason for advance directives. The most typical scenario in which these directives are appropriate is the gradual decline of mental and physical capacities which is proper to dementia, for example Alzheimer's disease. The possession of a living will written ahead of time of devastating effects of degenerative disease is considered especially urgent.

There are many other reasons in favor of advance directives in the form of a living will. The first one is related to legal problems concerning the end of life issues. In the world characterized by excessive sensitivity to personal autonomy and rights, the living will can decrease the risk of litigation and legal battles. Physicians and the loved ones of a patient can treat this document as a useful tool to solve possible legal problems.

¹² Gerard R. Cassagnol, *Living Wills Review: Five Reasons Why You Must Have a Living Will*, accessed June 4, 2015, <http://livingtrustnetwork.com/estate-planning-center/advance-directives/what-the-experts-say/living-wills-review-five-reasons-why-you-must-have-a-living-will.html>.

¹³ Rebecca Dresser, *Schiavo's Legacy: The Need for an Objective Standard*, The Hastings Center Report, vol. 35, no. 3 (2005): 20–22; Mary Schindler, Robert Schindler, Suzanne Schindler Vitadamo, Bobby Schindler, *A Life That Matters: The Legacy of Terri Schiavo—A Lesson for Us All* (New York: Werner, 2006).

Proponents underline that the living will is a way to preserve self-determination and autonomy. A patient can remain an active participant in important decisions regarding treatment or non-treatment and other critical issues. The choice of benefits and burdens of medical care is made while still in possession of one's own faculties. A living will can safeguard personal freedom when approaching the end of life. It is helpful to avoid dying in circumstances considered as unworthy or undignified. This document is also able to protect against maltreatment. In the medical world it is so easy to suffer from over-treatment or under-treatment. The life sustaining measures at the end of life can be overused or too little could be done on our behalf. A living will keeps these possibilities under control.

End-of-life issues can lead to anxiety and worries about the suffering of our loved ones. A living will can relieve these emotional turbulences. It is easier to face the future after making peacefully reasonable choices. The written document can be a great help to the family members, friends, and caregivers giving them a clear set of medical preferences. The statement about crucial decisions will increase in the loved ones a degree of confidence in their prudential judgments.

Advocates of the living will argue that this document can remove the painful burden of end-of-life decision which falls on the family members. On the one hand, they can, together with doctors and caregivers, make sound decisions to continue or to stop treatment. On the other, the decision making process for the family is less painful and done with a degree of confidence and closure.

The living will is useful in controlling financial issues. The cost of medical procedures is high and it is reasonable to manage prudently financial resources. Certain medical interventions are excessively expensive having limited value in the patient's final stages of life. A living will can prevent unnecessary spending and bring peace in the time of making important and costly decisions.

There is also one additional reason to work on a living will which cannot be overlooked. The composing of a living will can be treated as part of a wider process, that is, advance care planning. Individuals in consultation with their loved ones (family, friends) and physicians plan for medical care in the event of losing decision-making capacity.

The document of the Presidential Commission describes the care planning in the following way:

The process of preparing and executing a living will can be seen as a way to promote conversation among loved ones and with doctors about one's values and preferences regarding illness, medicine, and dying. Regardless of whether the explicit directives contained in the document eventually guide the patient's medical treatment, the mere exercise of preparing a living will can encourage greater thoughtfulness and communication between the patient, his family,

and his doctor as to how he would like to be cared for. Preparing a living will might be, for many people, the first occasion to articulate for themselves and for those who might care for them just how they would like their lives to end or how they would like to be cared for until the end.¹⁴

A dialogue about critical issues regarding values, healthcare, ageing and dying is needed in a basic structure of society, that is, in the family. It is worthy to talk about these topics in a way that the loved ones would have a clear image of personal preferences of someone dear to them. In a natural way, the loved ones are becoming health care proxies. Parents, husband or wife, children and members of the extended family are ordinary representatives of someone who has lost his or her ability to decide. Sometimes this is a privilege and duty of a friend, lawyer or physician who are legally appointed as proxies.

To become a health care proxy by family bonds or by appointment does not involve moral problems. The major area of controversies is written instruction, that is, the living will. In spite of decades of existence and public discussion in the most familiar with the living will society of the USA, only small percentage of people has signed this document.¹⁵

Summarizing this situation a few years ago, the President's Council of Bioethics stated the following:

Despite years of urging, most Americans do not have living wills, either because they would rather not think about their own dependence and death, or because they are wise enough to know that aging and dying sometimes mean placing oneself in the care of others. Not only are living wills unlikely to achieve their own stated goals, but those goals themselves are open to question. Living wills make autonomy and self-determination the primary values at a time of life when one is no longer autonomous or self-determining, and when what one needs is loyal and loving care. This paradox is at the heart of the trouble with this approach to care-giving.¹⁶

Thus, two factors are stressed in this conclusion. Some people do not have living wills because they are ignorant, or, saying it another way, they are indifferent toward planning their own remote future. Others lack a living will knowingly and willingly, considering this document as being useless. The mere fact of the presence of loved ones will suffice to have a peaceful assurance of one's future. Of course, ignorance or indifference is possible to overcome. There

¹⁴ *Taking Care*, 70.

¹⁵ Jeff L. Yates, Henry R. Glick, "The Failed Patient Self-Determination Act and Policy Alternatives for the Right to Die," *Journal of Aging & Social Policy* 94 (1997): 29–50; A. Fagerlin, C. E. Schneider, *Enough. The Failure of the Living Will*, The Hastings Center Report, vol. 34, no. 2 (2004): 32–42.

¹⁶ *Taking Care*, 55.

are positive examples of passing from indifference concerning a living will to a massive social movement supporting it.¹⁷ But the scale of this success is relatively small. Proxy directives serve the wise and helpful purpose of putting one's trust explicitly in the hands of loved ones who will bear the burden of providing care and making decisions. However, the paradox related to autonomy and self-determination remains without solution. An example of how the living will and proxy directives can operate follows in the case of Mr. A.

The Case of Mr. A.

Mr. A., a 74-year-old retiree, fell from his roof while doing yard work. He was stabilized and intubated at the scene and taken to the hospital, where he was found to have a high cervical fracture with impingement on the spinal cord. It was determined that he had no neurologic function below his face. He remained unconscious for two days, during which time he was transferred to a university hospital to undergo neurosurgical procedures. [...] Mr. A.'s living will, written before his accident, stated that he did not want any life-sustaining treatment in the event he was unable to communicate, and authorized the discontinuance of such treatment in the event it had been begun. His living will was shelved while the medical team evaluated whether improvement could be effected, and at the request of his family.

Three days after his fall, Mr. A. regained consciousness. [...] Even when he was asked to answer questions with eye blinks, he seemed unable to understand instructions and seemed unable to communicate using this method. Members of his family were with him constantly during his hospitalization, and they said that Mr. A. could understand them and could answer appropriately when he was addressed in Italian (he had emigrated from Italy 30 years prior). [...]

A week after the accident, Mr. A.'s physicians felt it was extremely unlikely that he would regain further neurologic function, and, as a quadriplegic, would require chronic ventilatory and nutritional support. The team did not tell Mr. A. about his prognosis [...]. The staff met with Mr. A.'s family members and told them his prognosis. [...] Since the staff believed that most likely Mr. A. could neither understand nor effectively communicate, they wondered why his living will was being 'overridden' by the hospital. When Mr. A.'s family overheard a nurse say that discontinuing care for Mr. A. was a 'no-brainer,'

¹⁷ Implementation effort of the social program "Respecting Your Choices" introduced in La Crosse, Wisconsin, in 1993 brought up to 85 percent of patients who had completed advance directives. Bernard J. Hammes, Brenda L. Rooney, "Death and End-of-Life Planning in One Midwestern Community," *Archives of Internal Medicine* 158, no. 4 (1998): 383–90.

because it was ‘required’ by his living will, the family feared that the staff was not looking out for Mr. A’s best interests, and that the staff wanted to ‘kill him.’

In response to the family’s concerns, nine days after the accident, the resident and intensive care fellow caring for Mr. A. in the ICU had a meeting with the family to restore communication and formulate a plan on how to proceed. [...] Mr. A.’s family said that they did not intend to advocate for heroic measures, but were concerned that the staff was ignoring Mr. A.’s best interests. They said they were advocating only for continuing care until Mr. A. was able to make a decision for himself about his future.

The family said that they did not know anything about Mr. A.’s living will, other than that Mrs. A., his wife, had also signed it. The family said that Mrs. A. was confused about the meaning of the living will, and the family was unsure what Mr. A. would want in this situation, despite what the living will stated. [...]

An hour later, the medical team and family, with a translator [...] gathered in Mr. A.’s room. [...] Through the translator, the fellow and resident told Mr. A. his prognosis, and Mr. A. indicated that he understood. As a way to introduce the topic of making decisions about treatment, the staff brought up Mr. A.’s living will, and then asked the translator to ask Mr. A. whether he wanted ‘to continue treatment, or to have treatment withdrawn, knowing that it would result in death.’ The translator asked instead, ‘Do you want to comply with the provisions of your living will, in which you signed a document that stated that if you were incapacitated you would want treatment withdrawn, or do you want to ignore your will and continue with treatment?’

The staff asked Mr. A. if he wanted to make a decision at that time, or if he needed more time. He responded in the affirmative when given the option of taking two days to make a decision. After the interview, the family, who were fluent in English and Italian, commended the translator for doing a wonderful and compassionate job. After this meeting, they said they realized that everyone was on the same side, working in Mr. A.’s best interest. On leaving the meeting, the fellow filled out a do-not-resuscitate (DNR) order for Mr. A., even though he had not spoken with Mr. A. or with Mr. A.’s family about it.

Two days after the family meeting that included Mr. A., the family approached the medical team and said they no longer felt that Mr. A. was able to communicate. His eye-blinking responses were no longer appropriate, and at times he did not blink in response to questions at all. After speaking with their priest, the family felt more comfortable making a decision on behalf of Mr. A. They requested the withdrawal of life support. The ventilator was turned off that evening and Mr. A. expired within minutes. His family expressed their gratitude and satisfaction to the staff.¹⁸

¹⁸ Ari VanderWalde, *Clinical Ethics Case Report*: “Questionable Capacity and the Guidance of Living Wills,” *Journal of Clinical Ethics* 22, no. 3 (2011): 250–55.

Discussion and Critical Remarks

The case of Mr. A. is very instructive. In a practical way, we can see how far it is possible to base one's own future on a living will and what the role of proxies in deciding the course of medical and life sustaining procedures is. Probably the greatest problem of Mr. A. was his poor understanding of possible clinical conditions. In the history of living wills, the earliest versions said nonspecifically about "heroic" measures approaching death. Later versions were focused on ordering the withholding or withdrawing of certain types of medical interventions such as resuscitation, respirator aid, the use of antibiotics or artificial hydration and nutrition. Mr. A.'s living will stated that he "did not want any life-sustaining treatment in the event he was unable to communicate." It is easy to understand what is meant by "life sustaining treatment" but the expression "unable to communicate" is not quite clear. The vague expression about ability to communicate can cover a wide spectrum of situations from a persistent vegetative state to a permanent failure of vocal chords. Mr. A. became a quadriplegic with restricted ability to communicate and had a poor overall prognosis. But in this state his capacity to communicate was probably suspended only temporarily. The poor understanding of clinical conditions is confirmed by Mr. A.'s wife who was confused about the content of the living will which she signed together with her husband. As Fagerlin and Schneider strikingly suggest, "Not only do people regularly know too little when they sign a living will, but often (again, we're human) they analyze their choices only superficially before placing them in the time capsule. An ocean of evidence affirms that answers are shaped by the way questions are asked. Preferences about treatments are influenced by factors like whether success or failure rates are used, the level of detail employed, and whether long or short-term consequences are explained first."¹⁹

There are no doubts that it is necessary with this type of written instruction to consult with a physician and loved ones. It can safeguard the coherence of the values of a person and his basic convictions on life and death. As we could see, Mr. A. and his wife did not consult about the content of their living wills with the rest of the family. The family was confused about the meaning of living will and "unsure what Mr. A. would want in this situation, despite what the living will stated." In other words, they were aware that the content of the living will was not expressing Mr. A.'s convictions.²⁰

¹⁹ Fagerlin, Schneider, *Enough*, 33.

²⁰ Edmund Pellegrino, based on years of experience in dealing with patients in clinical conditions, described the need of consultation in the following way: "Patients especially need the input of others if their own choices are to be genuine ones. Physicians are needed to provide information and to discuss this information with patients [...]. Patients must compare their values

Three days after the fall, Mr. A. regained consciousness so it was possible to communicate with him. In this context, the living will lost its weight. It was possible to establish his prognosis and to ask him what he would decide to do in the new situation. Unfortunately, the living will written some time ago was treated as a permanent statement of Mr. A. without the possibility to override it. All who were involved in the case: physicians, nurses, and family members were convinced that they were working in Mr. A.'s best interest, but they ignored the fact that his living will had no absolute value. So the help of the translator who asked: "Do you want to comply with the provisions of your living will, in which you signed a document that stated that if you were incapacitated you would want treatment withdrawn?" probably only brought more confusion to a quadriplegic patient. Finally, he never gave an answer. Next two days which he took for consideration brought him back to unconsciousness.

Mr. A.'s case invites us also to a reflection on the autonomy of a patient. It is clear that Mr. A.'s will was not respected. The physician without consultation with Mr. A. and his proxies wrote a DNR order. The patient's autonomy is seen as a protection against medical paternalism.²¹ In the light of paternalism, the physician, as better informed, considers his or her duty to decide on behalf of the patient's best interests. It is wrong to override the free choice of a patient, as he or she cannot be treated instrumentally.

On the other hand, it is valuable to ask how far it is possible to respect a patient's autonomy. Is there any limit to a patient's choices or can he demand whatever he wishes? If the patient's choice is written in a living will, should it be absolutely respected? At first, Mr. A.'s living will was ignored. The medical team was doing everything to ameliorate his condition even though the living will stated that if he was unable to communicate he did not want any life-sustaining treatment. Did they proceed in a suitable way? I think they did. The fact is that after regaining consciousness Mr. A. requested two days to think about the provisions written in his living will and was not protesting that the medical team ignored them.

It is evident that it is not easy to understand one's own medical situation and make irreversible decisions. Probably, two days would not have been enough for

with those of others in the context of some community of belief which they accept in whole or in part. Patients cannot identify with their current choices without reference to some structure of values which they formed in the past and which they reaffirm or reject at the moment of choice." Edmund D. Pellegrino, "Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship," *Journal of Contemporary Health Law and Policy* 10, no. 2 (1994): 50–51.

²¹ Beauchamp and Childress define "paternalism" as "the intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefitting or of preventing or mitigating harm to the person whose preferences or actions are overridden." Tom L. Beauchamp, James F. Childress, *Principles of Biomedical Ethics*, 6th ed. (New York: Oxford University Press, 2009), 208.

Mr. A. to make an ultimate decision. It is hard not to agree with an interesting observation of Carl Schneider:

People do not predict their own future happiness very accurately. Now part of what's going on here is that, in fact, it's true that experience is in many ways the best teacher, and experience often counsels us to reconsider our opinions. People these days routinely recite the mantra that the quality of life is more important than the quantity of life, and they believe it up to the point at which the quantity of life actually becomes an issue, at which point they become remarkably unwilling to give up increments of quantity in order to get fairly large increments of quality. [...] People who are very ill think that their lives are much more satisfactory than observers of their lives think.²²

We asked about the limits of the patient's autonomy. Far from supporting paternalism, it is necessary to underline that one of the limits of a patient's autonomy is the autonomy of a physician or other medical agent. A living will can contain requests which go against the physician's conscience. Edmund Pellegrino reflects on this in the following way:

The autonomy of the physician is often neglected. This philosophy has serious defects. The physician-patient relationship is one of mutual obligations—like any truly ethical relationship. The physician as a human being has the same claim to respect for his or her capacity, to make personal choices, to follow his or her conscience about what is good medicine and what is morally acceptable as a person. Personal and professional ethics are not fully separable from each other. Therefore, the patient's moral right of autonomy must be balanced with respect for the physician's autonomy. Autonomy cannot be a unilateral moral right for either patients or physicians.²³

We have to remember that the earliest proposal of a living will written by Kutner was clearly related to euthanasia.²⁴ If the first commandment of the medical profession states *primum non nocere*, how is it possible to justify medical decisions which go directly against human life? We can imagine this only in the civilization of use in which people are treated as objects equipped with consciousness. But this civilization is not the only one that governs our world. Inherent human dignity should be respected at any period of life, especially when life is stigmatized by illness and suffering. Because of this—as it was precisely pointed out by William E. May,

²² Carl E. Schneider, *Session 2: Aging and Care-Giving: Options for Decision-Making*, December 2, 2004, accessed May 5, 2015, <https://bioethicsarchive.georgetown.edu/pcbe/transcripts/dec04/session2.html>.

²³ Pellegrino, *Patient and Physician*, 51.

²⁴ Cf. *ibid.*, n. 5.

human autonomy is not unlimited. Its *rightful* exercise enables us to achieve our fulfillment, our perfection, but it is subservient to our *good as persons*. [...] If our choices seriously undermine in us our capacity to flourish as human persons, and if, *a fortiori*, they aim to damage aspects of this capacity in others, there is no reason to respect such choices. And the intentional killing of ourselves or others, no matter what the reason, is a choice that sets us against the inherent goodness human life.²⁵

There are no doubts that autonomy has a relative value. What is absolute is human dignity. Based on this dignity a patient is entitled to write advance directives in the form of a living will. Mr. A. did this, however, as we could see, on the one hand, his living will was not well formulated and on the other, it was not used correctly. What then is the function of a living will, and how should it be used in clinical conditions? It is understandable that it cannot be disregarded.

Simply ignoring the patient's written instructions would give too little regard to the person's former beliefs about the shape and character of a good life. But giving those wishes trumping power may force caregivers to forgo doing what is best for the person who is now entrusted to their care; as moral agents themselves, caregivers cannot simply do what they were told but must also try to do what is best.²⁶

Reading Mr. A.'s case at the end of the story we find unexpectedly a short description of the final solution. It does not give an impression of a happy ending. The family, based on the inability to communicate (incorrect eye-blinking) made the decision to withdraw the life support. In a few minutes after turning off the ventilator Mr. A. expired. The controversy over this description can come partially from the incomplete knowledge of the precise clinical condition of the patient. We do not know if the machine assisted or replaced completely Mr. A.'s spontaneous breathing. The fact is that after turning it off Mr. A. passed away. His neurological condition is also unknown. It is obvious that his brain was not severely damaged. The ability to communicate and understand indicated that the higher brain functions were working properly. Probably, the lack of communication was only temporary and after a certain time it could have been restored. Mr. A. was not terminally ill. He could live for years after the accident but surprisingly he even did not have a chance to confirm his decisions written in the living will. Why did his family make this drastic choice? Is there a limit in proxy decisions?

²⁵ William E. May, *Catholic Bioethics and the Gift of Human Life* (Huntington, IN: Our Sunday Visitor, 2000), 248–49.

²⁶ *Taking Care*, 84.

The family, as we saw, was doing everything in Mr. A.'s best interest. Their decision in consultation with the priest had no homicidal intention. But I doubt if this was the best decision. A good intention is only one of the factors which make a human act good. The act itself should be morally good. More things could have been done for Mr. A., especially additional attempts to communicate with the patient. A second opinion on the neurological condition and better understanding of the role of a living will could have changed the end of this story. The limits of proxy decisions are the same as in the case of the patient's autonomy, that is, human dignity. It should never be violated even at the request of a patient.

Conclusion

Advance directives are written or oral statements which allow people to decide on their medical preferences when they lose decision-making capacity. They have two forms. One is called a living will which is a written statement and the other is oral, which is called health care proxy. The history of advance directives is related to an attempt to introduce the possibility of euthanasia and controversial legal battles over the right to withdraw life sustaining treatment for patients who were unconscious. Advance directives are legally accepted in many countries but they are still a topic of moral controversies. They are proposed as a way to preserve autonomy and self-determination, avoid legal problems, ease anxiety and worries of the loved ones, manage financial issues better and promote conversation about the person's values and preferences regarding illness, suffering, and dying. These important goals and decades of advertising them did not make them popular. Major moral problems concern the living will. Life is dynamic and even the best scenario is unable to fit an actual clinical situation. Many times provisions stated in living wills go against the good of unconscious patients. People usually do not take sufficient time to analyze their content when they sign them, but later they are submitted to consequences of superficial decisions. Autonomy itself, which is the primary value of living wills, can be easily misunderstood. This value has its limits in human dignity and the autonomy of physicians and other members of a medical team. Autonomous decisions stated in a living will cannot be treated as something non-negotiable. They cannot go against the good of a person. The good of ill and incompetent patients is the major concern of health care proxies. Their primary function is to fulfill the patient's will and to make crucial decisions on behalf of incompetent patients in a clinical condition. They have to act with reference to the structure of the patient's values and respect human dignity.

Bibliography

- Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics*. 6th ed. New York: Oxford University Press, 2009.
- Brauer, Susanne, Nikola Biler-Adorno, and Roberto Adorno. *Country Reports on Advance Directives*. Accessed May 3, 2015. http://www.ethik.uzh.ch/ibme/newsarchiv/advance-directives/Country_Reports_AD.pdf.
- Cassagnol, Gerard R. *Living Wills Review: Five Reasons Why You Must Have a Living Will*. Accessed June 4, 2015. <http://livingtrustnetwork.com/estate-planning-center/advance-directives/what-the-experts-say/living-wills-review-five-reasons-why-you-must-have-a-living-will.html>.
- Colby, William H. *Long Goodbye: The Deaths of Nancy Cruzan*. Carlsbad, CA: Hay House, 2002.
- Dresser, Rebecca. *Schiavo's Legacy: The Need for an Objective Standard*. The Hastings Center Report, vol. 35, no. 3 (2005): 20–22.
- Fagerlin, Angela, and Carl E. Schneider. *Enough. The Failure of the Living Will*. Hastings Center Report, vol. 34, no. 2 (2004): 32–42.
- Fisher, Gary S., James Tulsky, and Robert M. Arnold. *Advance Directives and Advance Care Planning*. In *Encyclopedia of Bioethics*, edited by S. Garrard Post. Vol. I, pp. 74–79. New York: Macmillan, 2004.
- Hammes, Bernard J., and Brenda L. Rooney. "Death and End-of-Life Planning in One Midwestern Community." *Archives of Internal Medicine* 158, no. 4 (1998): 383–390.
- Jantos, Małgorzata. "Czy decydujemy o swojej śmierci?" *Kwartalnik filozoficzny* 42, no. 3 (2014): 171–185.
- John Paul II. Letter to Families *Gratissimam Sane*. February 2, 1994. Accessed April 4, 2015. http://w2.vatican.va/content/john-paul-ii/en/letters/1994/documents/hf_jp-ii_let_02021994_families.html.
- Kutner, Luis. "Due Process of Euthanasia: The Living Will, a Proposal." *Indiana Law Journal* 44, no. 3 (1969): 539–554.
- May, William E. *Catholic Bioethics and the Gift of Human Life*. Huntington, IN: Our Sunday Visitor, 2000.
- McFadden, Robert D. *Karen Ann Quinlan, 31, Dies: Focus of '76 Right to Die Case*. Accessed May 3, 2015. <http://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html>.
- Pellegrino, Edmund D. "Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship." *Journal of Contemporary Health Law and Policy* 10, no. 2 (1994): 47–68.
- Schindler, Mary, Robert Schindler, Suzanne Schindler Vitadamo, and Bobby Schindler. *A Life That Matters: The Legacy of Terri Schiavo—A Lesson for Us All*. New York: Warner, 2006.
- Schneider, Carl E. *Session 2: Aging and Care-Giving: Options for Decision-Making*. December 2, 2004. Accessed May 5, 2015. <https://bioethicsarchive.georgetown.edu/pcbe/transcripts/dec04/session2.html>.
- Śliwka, Marcin, and Anita Gałęska-Śliwka. "Regulating End of Life Decisions in Poland. Legal Dilemmas." *Advances in Palliative Medicine* 10, no. 2 (2011): 49–56.
- Syska, Maciej. *Medyczne oświadczenia pro futuro na tle prawnoporównawczym*. Warszawa: Wolters Kluwer, 2013.

- The President's Council on Bioethics. *Taking Care: Ethical Caregiving in Our Aging Society* (September 2005). Washington D.C., 2005.
- 42 U.S. Code Service sections 1395i-3, 1395l, 1395cc, 1395bbb. Accessed June 1, 2015. <http://uscode.house.gov/>.
- VanderWalde, Ari. "Clinical Ethics Case Report: Questionable Capacity and the Guidance of Living Wills." *Journal of Clinical Ethics* 22, no. 3 (2011): 250-255.
- Yates, Jeff L., and Henry R. Glick. "The Failed Patient Self-Determination Act and Policy Alternatives for the Right to Die." *Journal of Aging & Social Policy* 9, no. 4 (1997): 29-50.

Witold Kania

Problèmes moraux liés aux directives anticipées

Résumé

La lettre *Gratissimam Sane* souligne que la civilisation contemporaine appuyée sur l'utilitarisme traite les gens comme des « objets » et non comme des « personnes ». La civilisation utilitariste influence aussi la vie familiale. Dans ce contexte, l'article analyse le problème de directives anticipées. L'introduction constitue le précis historique des directives anticipées. Les origines des directives anticipées sont liées aux mouvements promouvant l'euthanasie et aux décisions juridiques controversées concernant les patients qui ont perdu la capacité de prendre des décisions conscientes. Ensuite, l'auteur présente les causes principales pour lesquelles on rédige un testament de vie ou désigne un mandataire dans le cadre de la représentation du patient. La deuxième partie présente le cas clinique de Monsieur A. Ce cas est une bonne illustration des problèmes liés à l'interprétation et l'application des directives anticipées. L'article finit par une discussion sur *casus* qui se concentre autour de la dignité et de l'autonomie aussi bien du patient que du médecin, ainsi qu'autour des limites des décisions prises au nom du patient.

Mots clés: directives anticipées, euthanasie, désignation d'un mandataire dans le cadre de la représentation du patient, autonomie, dignité humaine

Witold Kania

Problemi morali realtivi alle direttive anticipate

Sommario

La lettera *Gratissimam Sane* sottolinea che la civiltà moderna, basata sull'utilitarismo, tratta le persone come "cose" e non come "persone". La civiltà dell'uso influisce anche sulla vita familiare. In questo contesto, il documento analizza il problema delle direttive anticipate. L'introduzione contiene dei cenni storici sulle direttive anticipate. Le origini delle direttive anticipate sono collegate a movimenti che promuovono l'eutanasia e a controverse decisioni giudiziarie relative a pazienti che hanno perso la capacità di prendere decisioni consapevoli. Sono poi presentati i motivi principali per i quali si redige il testamento biologico o si delega qualcuno tramite procura medica. La seconda parte presenta il caso clinico del signor A.

Questo caso illustra bene i problemi connessi all'interpretazione e all'applicazione delle direttive anticipate. L'articolo si conclude con la discussione del caso, incentrata sulla dignità e sull'autonomia sia del paziente che del medico nonché sui limiti delle decisioni prese in nome del paziente.

Parole chiave: direttive anticipate, eutanasia, procura medica, autonomia, dignità umana